

Disability Rights UK

Disability
alliance



the disability rights people



PIP assessment criteria and thresholds consultation

Disability Rights UK response: May 2012

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Disability Rights UK

Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012. We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK's objectives are:

- To mobilise disabled people's leadership and control;
- To achieve independent living in practice;
- To break the link between disability and poverty; and
- To put disability equality and human rights into practice across society.

Summary and context

We are very concerned that the Government's approach to abolishing working age Disability Living Allowance (DLA) risks being implemented without an adequate assessment of the potential impact on disabled people, families and government expenditure.

We believe that the Department for Work and Pensions (DWP) plans to remove eligibility for support for 500,000 disabled people will undermine disabled people's equality of opportunity and heighten poverty, disadvantage and inequality. This is particularly worrying given the reduction in support from councils and other measures disproportionately affecting disabled people.

This 'cumulative effect' of retracting support for disabled people was highlighted by the recent Equality and Human Rights Commission investigation¹ and the Joint Committee on Human Rights' inquiry into the UK Government's implementation of disabled people's right to independent living². We are yet to see an adequate response from DWP as to how the potential impact of Government proposals will affect disabled people's lives.

This is particularly the case with the abolition of working-age DLA and the creation of a new benefit which our members are already referring to as 'DLA-Lite' given the poor contribution it will make in comparison with the support available from the existing system. Many disabled people and our members also feel that the new benefit will also create an 'armchair existence' for thousands of disabled people. This is especially through its minimised focus on essential daily activities, lack of indoor mobility needs, and more restrictive eligibility.

We are concerned that the overarching Government objective is to cut 20% of DLA/PIP funding by 2015/16. We believe that the proposed assessment for the 'replacement benefit (the 'Personal Independence Payment' or PIP) is designed not to meet genuine needs or support disabled people with higher costs of living, but to meet an arbitrary reduction in expenditure in an unduly hasty timeframe.

Given the experience of the introduction of the Work Capability Assessment and face to face interviews for out of work benefits which costs £100million per annum to run plus a further £26million in the last financial year in appeals, it is essential that the Government approach the new PIP assessment process very carefully. It is also essential that disabled people are able to understand the new processes, have accessible communications with/from DWP and any assessment agencies and can source expert, independent information and advice to help through the new systems and processes.

DWP suggests disabled people with the highest needs will continue to access support. But the proposed assessment criteria risk significantly

¹ See: <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/section-31-assessment-of-hm-treasury/the-assessment-final-report/>

² See: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/inquiries/protecting-the-right-of-disabled-people-to-independent-living/>

disadvantaging disabled people and their families. Even people with the highest levels of need are likely to lose support under current plans – including over a quarter of a million (280,000) disabled people losing eligibility for high rate DLA mobility payments (or ‘enhanced PIP mobility payments’).

We are concerned that the assessment has been devised by a very limited group of (as the consultation document puts it) ‘trained health professionals’ and without adequate input and involvement of disabled people. We are concerned that recommendations and suggestions from the assessment group’s disabled representatives cannot be clearly identified in the current proposals.

We are also concerned that the sample group of disabled people used to test the initial assessment plans and subsequent trialling of proposals may not reflect the impairment types of all the disabled people receiving DLA and especially those with fluctuating, multiple or rare health conditions/impairments. Our fear is that a combination of an inadequate sample, a restrictive set of descriptors and weightings and an undue haste will mean the DWP estimate of 500,000 disabled people likely to lose support is far too conservative.

We are very grateful for the extension to the formal deadline for submitting responses to the consultation (30th April) following our meeting for our member organisations which only occurred on that date after having to be postponed during the full consultation period. We are assured our response will still be considered and are grateful for this information from DWP.

Disability Rights UK analysis of potential DLA/PIP plans

Disability Rights UK is a new charity, formed through the merger of Disability Alliance, NCIL and Radar. In February 2011 our former charities raised concerns with the Department for Work and Pensions (DWP) that government proposals for abolishing Disability Living Allowance (DLA) for people 16-64 years of age needed properly assessing³. We attempt to provide some further analysis of government plans in this document.

The purpose of our analysis is to examine what disabled people predict is likely to happen if government changes mean they are no longer eligible for support. We use DWP estimates as far as possible to examine potential costs to government.

³ Disability Rights Partnership: ‘End of a Lifeline?’, 2011. See: <http://www.disabilityalliance.org/r68.pdf>

Our fear is that the full impact on disabled people and the associated costs to government are being ignored in the rush to deliver a 20% saving in overall DLA expenditure by 2015/16⁴ by introducing a new benefit. The Government aims to achieve this by abolishing working age DLA and introducing a Personal Independence Payment benefit (PIP) with lower numbers of disabled people eligible for support.

The Government's approach to abolishing DLA has appeared to assume expenditure is 'deadweight' and achievable without any knock on effects to other government revenue or expenditure. This is a falsehood.

Our fears over the lack of adequate assessment of the impact of losing support are shared by our members and other organisations. The Joint Committee on Human Rights (JCHR) also raised similar fears in March 2012⁵. The JCHR reported that its inquiry into disabled people's right to independent living:

"received evidence that impact assessments of current reforms were not adequately carried out, and did not take into account the likely cumulative impact of reforms on disabled people. We therefore argue that the Government should publish a unified assessment of the likely cumulative impact of the proposals on independent living."

The JCHR report substantiates our view that the Government must properly assess proposals which disproportionately affect disabled people and could undermine rights to equality of opportunity.

The absence of adequate government analysis despite legitimate questions posed by us, other disabled people and organisations about the impact of losing DLA is worse than disappointing; it is irresponsible. The potential costs to government are significant and must not be ignored, especially in the context of a fragile UK economy.

There are further risks the Government should not ignore. In July 2011 Disability Alliance outlined the clear case for a legal challenge of government plans if adequate impact assessments were not provided⁶.

In light of the Government's failure to demonstrate full analysis of the impact of proposals and the conclusions of the JCHR, we are examining our options to pursue full action now welfare reform legislation has been enacted.

⁴ As set out in the 2010 Emergency Budget and subsequent DWP documents.

⁵ Joint Committee on Human Rights 23rd Report: 'Implementation of the Right of Disabled People to Independent Living' 1 March 2012. See: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/independent-living-report/>

⁶ See: <http://www.disabilityalliance.org/dlachallenge.htm> for further information.

Potential costs of 500,000 disabled people losing eligibility for support

In the absence of adequate government analysis, we have reviewed DWP estimates for the number of disabled people who will lose eligibility for help⁷. Under the abolition of DLA for working age disabled people and the introduction of Personal Independence Payments, DWP have revealed half a million less disabled people will be eligible for support.

In the largest recent survey of disabled people and use of DLA⁸ more than 1,700 responses were received. 82% were from disabled people using DLA or carers supporting disabled people using DLA. In open questions, respondents highlighted the risks of losing DLA to three areas we examine in more detail below:

- 56% of the people in work said they would have to stop or reduce work if they lost DLA;
- 16% suggested cuts to DLA will result in higher NHS use; and
- 14% suggested a likely need for more use of council services.

Using these estimates of how disabled people they might be affected if they lost DLA and the DWP estimate that 500,000 less disabled people will be eligible for support, we have split our analysis into potential: work; NHS; and council costs.

1) Potential impact of DLA plans on disabled people's ability to work

DLA is not an out of work benefit. It was introduced from 1992, under the last Conservative government, to help with disabled people's routine higher living costs⁹. Disabled people in work can experience higher living costs than other workers and disabled people out of work due to additional travel in particular.

DLA supports many disabled people in work. This is despite estimates for the government that 56% of the people receiving DLA have four or more health conditions (and 93% two or more health conditions)¹⁰.

DWP estimates about 9% of the people receiving DLA are in work¹¹. However, if all DLA recipients are included (i.e. children and people over retirement age) the in-work figure is necessarily smaller as a percentage than

⁷ In January 2012 DWP published a consultation on PIP assessment thresholds. See: <http://www.dwp.gov.uk/docs/PIP-assessment-thresholds-and-consultation.pdf>

⁸ Conducted by Disability Alliance between December 2010 and February 2011, with results published online at: <http://www.disabilityalliance.org/r68.pdf>

⁹ The evidence base for disabled people's higher costs is substantial; see: SOURCE.

¹⁰ Sainsbury, R et al 'Evaluation of Disability Living Allowance and Attendance Allowance', 1995. Department of Social Security Research Report No.41; see: <http://research.dwp.gov.uk/asd/asd5/rrep041.pdf>

¹¹ DWP 'Disability Living Allowance and work: Exploratory research and evidence review' 2010; see: <http://research.dwp.gov.uk/asd/asd5/rreports2009-2010/rrep648.pdf>

if just analysing the working age group affected by the initial phase of DLA abolition¹².

The figures for disabled people in work and receiving DLA vary. In one study, 20% of the disabled people receiving DLA and no other benefits were in work and 40% of the single, disabled people living with their parents were also in work¹³. Some of the research distortion on work is caused by a failure to record part time work (especially under 16 hours). In the Disability Alliance survey 27% of respondents were working either full or part time and 12.5% were receiving working tax credit.

However, for the purposes of our analysis we have deliberately selected the low 9% estimate of how many disabled people using DLA are in work to ensure we do not exaggerate potential costs. But it should be noted that the final figure affected is likely to be higher.

The total loss is likely to be higher partly due to the low estimate of in-work disabled people using DLA. But the nature of the proposed assessment system for PIP under government plans and the policy aspiration of 'targeting PIP at disabled people with the highest needs'¹⁴ means it is more likely disabled people in work are at risk of being made ineligible for support.

Using the largest recent survey of people receiving DLA, 56% said they may have to leave work if they lost support¹⁵. DWP suggests 500,000 disabled people will lose eligibility for support from 2013. If 9% of the 500,000 disabled people losing eligibility were in work this would be 45,000 people.

If 56% of the 45,000 affected did lose work this would represent 25,200 disabled people unable to retain employment; the risk to disabled people's opportunities to retain or acquire employment is very real.

This would massively increase the bill for abolishing DLA with losses to government coming immediately from lost National Insurance and Income Tax contributions.

According to the National Statistics Office 2012 figures, average UK earnings are £26,100 per year¹⁶. Whilst disabled people in work earn less than non-

¹² Initial plans are for people aged 16-64 to be moved off DLA. The government has indicated children will be the next tranche to be moved off DLA, followed by older people at an unspecified later date.

¹³ DSS (forerunner to DWP) 'Disability Benefits and Employment' Richard Berthoud and Karen Rowlingson, 1996; see: <http://research.dwp.gov.uk/asd/asd5/rrep054.pdf>

¹⁴ See, for example, the DWP homepage on PIP: <http://www.dwp.gov.uk/policy/disability/personal-independence-payment/>

¹⁵ See: http://www.disabilityalliance.org/r68.doc#_Toc285815634

¹⁶ See: <http://www.ons.gov.uk/ons/rel/ashe/annual-survey-of-hours-and-earnings/2011-provisional-results--soc-2010--stb---ashe-results-2011--soc-2010-.html>

disabled colleagues on average, disabled earners' income is not provided in one credible source so we have had to use the national average to estimate National Insurance (NI)/income tax losses to the Treasury.

The 2012/13 income tax rate on the average salary would be £3,599 and the NI contribution would be £2,220.96 (i.e. a 'take home' pay of £20,280.24). The total potential Treasury contribution on the average wage is currently £5,819.96 from a single disabled earner. Multiplied by the number of disabled people possibly leaving work (25,200) the Treasury loss could be as much as £146.7 million a year.

Many disabled people will not earn the national average and the Treasury is also likely to recoup savings from non-payment of tax credits to disabled people no longer in work. But our analysis does not aim to present absolutes; we simply intend to highlight potential failures and risks of the government's lack of assessments. DWP have provided no better figures to use at this stage for analysing government plans.

Our 25,200 figure for disabled people possibly leaving work is also potentially a very conservative estimate. Using an 18% halfway figure of the 9% DWP estimate and the 27% of respondents in the Disability Alliance survey including part time workers, 90,000 disabled people in work could be affected. The total number of disabled people possibly losing work could be 50,400. This could mean the Treasury loses (based on average income) up to £293.3 million per year in NI and income tax payments.

There are also potential longer-term losses that are more difficult to estimate. DLA has also been viewed by some disabled people as a useful 'top up' for low paid work and supported some disabled people to stay in work but reduce hours after developing a health condition and/or impairment, helping replace income from lost hours of work¹⁷. DWP reported in 2010 that many disabled people also use DLA to retain connections to employment opportunities¹⁸. In the recent Disability Alliance survey disabled people reported using DLA to help participate in volunteering, or supporting a partner/carer to stay in work. Many also suggested that DLA helped pay for rising fuel costs for work for example – which low salaries and other support might not otherwise meet¹⁹. This linkage could also be broken under PIP plans but is unquantifiable as a cost for the purposes of our analysis.

The potential for the government to miscalculate savings from such a large group of people being prevented from retaining current employment, maintaining work-related activities and current productivity levels is high. It is

¹⁷ See: <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep648.pdf>

¹⁸ See: <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep649.pdf>

¹⁹ See: http://www.disabilityalliance.org/r68.doc#_Toc285815634

inexplicable that DWP have failed to provide data on this potential risk. But DWP has repeatedly ignored the issue of ensuring government plans to not prevent disabled people retaining work.

Lost Treasury revenue is not the only cost if disabled people lose work under the diminishing eligibility for DLA/PIP support. A further cost of disabled people being prevented from retaining employment is out of work benefits.

Other potential costs of losing work: out of work benefits

The government would not just lose NI/income tax contributions from disabled people unable to retain employment. The same disabled people would be entitled to out of work benefits. This makes costs to government higher.

If all those losing work were placed on Jobseeker's Allowance (JSA) it would cost £71 for people over 25 a week and £56.25 per week for the disabled people under 25 years of age at current benefit rates.

Of the 1.83 million working age people receiving DLA in August 2011 just 207,840 were under 25²⁰. This represents 11.4% of the total working age caseload. If the age group losing eligibility to PIP from 2013 is evenly distributed then 25,200 losing payments would mean 2,873 under 25 years of age. This would cost £8.4 million per year in out of work benefits. Obviously, as this group gets older their benefit payment rate will increase.

The cost of the people over 25 years of age (22,327 disabled people) would be far greater at £82.4 million per year (£71 per week).

As a minimum, the out of work benefits bill could be £90.8 million a year if 25,200 disabled people lost work as a result of DLA plans. We believe the total figure for disabled people losing work could be higher and that many disabled people would qualify for higher levels of out of work benefits.

If the 18% losing work estimate were realised under government plans, the total JSA cost would be higher. If 50,400 lost work and 11.4% were under 25 years of age this would represent 5,746 under 25 and 44,654 over 25. The JSA payments would cost £16.8 million and £164.9 million respectively; £181.7 million in total.

- ESA payments

But these figures are based on JSA. Disabled people could be entitled to Employment and Support Allowance (ESA). ESA is paid at a higher rate than

²⁰ DWP statistics; see:

http://83.244.183.180/100pc/dla/cnage/ccgor/ccclient/a_carate_r_cnage_c_ccgor_p_ccclient_working_age_aug11.html

JSA: £99.15 per week for people over 25 years of age (£5,155.80 per year) and £84.40 for the under 25 age group (£4,388.80 a year)²¹.

If all 25,200 possibly losing work received ESA and 11.4% of the people affected were under 25, this could increase the out of work benefits cost to £12.6 million a year for the under 25s and £115.1 million for people over 25 years of age. This total reaches potentially £127.7 million in out of work benefits unaccounted for by DWP.

Using 18% to estimate the number of disabled people in work that could be affected this rises further. If 5,746 were to lose employment under 25 years of age and 44,654 over 25 and all were to access ESA the cost to DWP would be £25.2 million and £230.2 million respectively; £255.4 million in total.

- Other out of work costs

Other benefit costs include the changes to housing benefit that could occur through lost employment. A single disabled person over 35 earning £26,000 a year and renting privately in Islington would get about £55 per week housing benefit currently. This would rise to £250 a week if unemployed. A typical example outside London could mean a similar disabled person in Loughborough currently receiving no housing benefit in work (due to lower rent) could be eligible for £86 per week unemployed.

Also, if disabled people have mortgages, there may be no help available whilst working full-time, but there would be entitlements for financial support if made unemployed as a result of DLA losses (after waiting periods and for 2 years only). These costs are important but have also been ignored in the rush to deliver a 20% reduction in DLA expenditure.

The costs to government of failing to retain support for disabled people in work are substantial. But, despite numerous requests on this issue from disabled people and organisations²², these figures were not made available to Parliament during the passage of the Welfare Reform Bill and do not appear to have been adequately analysed by DWP.

Paying to assess benefit eligibility

Accessing out of work benefits is not free. Just paying benefits to people ignores the new gateway to accessing out of work payments. The Work Capability Assessment (WCA) is the route for new claimants. It currently

²¹ These figures are for people in the Work-Related Activity Group of ESA. It is very likely that some disabled people affected could secure Support Group ESA payments which are worth £105.05 for people over 25 and £90.30 for people under 25. About 15% of the people currently seeking ESA receive this level of payment. This would increase out of work benefit payments to government further but we have not included an estimate for this group in our analysis.

²² For an example of disability organisations raising this issue, please see the summary of recommendations included in the Disability Rights Partnership response to the DWP DLA/PIP consultation submitted in February 2011, available online at: http://www.disabilityalliance.org/r68.doc#_Toc285815634

costs £100 million per year to run by Atos Healthcare²³.

Atos are supposed to see 15,000 people per week. They do not hit this target but the £100 million per year figure is worth £128 per assessment (using 780,000 maximum assessments per year). Assessing 25,200 people being moved out of work as a result of losing DLA would then cost an additional £3.2 million.

If 50,400 disabled people lost work the cost for assessments for out of work benefits rises to £6.5 million.

It is estimated that 40% of initial WCA decisions are appealed (due to inaccurate assessment processes which fail to identify disabled people's genuine needs adequately). This is relevant expenditure, but we are excluding appeals costs for the purposes of this analysis.

However, a further essential cost to include is the price of the new assessment for PIP eligibility. DWP is proposing a new face to face PIP assessment to examine eligibility. The contracts to deliver this assessment are not yet awarded but the impact assessment for the Welfare Reform Bill included £675 million to assess up to 2.2 million people²⁴.

2) Potential impact of DLA plans on the NHS

The new assessment process, measuring eligibility for about 2.2 million no longer able to access DLA, not only costs government to deliver. It also requires the disabled people being assessed to provide independent medical evidence. For most disabled people this will be accessed via a GP.

Estimates for the cost of a GP appointment vary. The BBC have suggested £18²⁵ based on an estimated £180 million loss to the NHS from 10 million missed GP appointments and 5 million missed practice nurse appointments. If the new assessment process resulted in 2.2 million people receiving just one £18 appointment the total cost would be £39.6 million.

But a more credible costing for a GP appointment is £60 provided by the Royal College of Nursing using 2009 NAO statistics²⁶. This would mean a total cost of £132 million to the NHS alone for the 2013-16 period.

Many disabled people will require more than one appointment and many more will need to see a more specialised consultant to access the information

²³ SOURCE

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²⁵ See: <http://news.bbc.co.uk/1/hi/health/4177230.stm>

²⁶ See: http://www.rcn.org.uk/_data/assets/pdf_file/0008/317780/003598.pdf

required. These substantial costs are unaccounted for in the figures made public by DWP and were not available to parliament during the passage of the Welfare Reform Act.

Furthermore, the Disability Alliance survey of disabled people published last year suggested 16% would be more reliant on the NHS. If this group has just one further appointment with a GP this is the equivalent of 80,000 additional appointments (using 500,000 as the group worst affected by being made ineligible for further support). This would cost £4.8 million a year to the NHS using the £60 costing per appointment.

This does not account for people hospitalised as a result of losing support. Many disabled people told Disability Alliance that hospitalisation would be required due to an inability to manage health needs (eg through not being able to afford prescriptions, attend routine appointments or cover other health-related costs).

The average hospitalisation period in England is six days²⁷. The weekly cost of using a hospital bed is estimated to be £1,750-£2,100²⁸. Prices vary depending on condition and acute beds cost more. One estimate suggests a £400 per day cost for bed use (£2,800 per week) but we use the lower average range for the purposes of this analysis to avoid inflating costs.

If a bed costs £1,750 per week a six day stay would be £1,500. If the bed was £2,100 a week then a six day treatment period would cost £1,800. The number of disabled people who reported to Disability Alliance being more likely to use NHS services if they lost DLA was 16%. Using the DWP 500,000 estimate for lost eligibility this could mean 80,000 disabled people requiring an average hospital stay and could cost between £120 million and £144 million a year.

This cost was not identified by DWP in DLA documents made public during the course of welfare reform plans despite requests. Even if the total estimated number of hospitalisations is high, the figures reveal that if even 10% of the disabled people are accurate in requiring an in-stay, this could cost at least £12 million per year.

The Commons Public Accounts Committee has also estimated that 'bed blocking' costs the NHS £170 million per year. If more people need treatment, there is a lower ability to self-manage conditions (as a result of losing financial support under DLA plans), and if less support is available from

²⁷ Using NHS Information Centre statistics for 2010/11 mean hospital stays; see:

<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=212>

²⁸ See: <http://ageukblog.org.uk/2011/01/07/council-funding-cuts-could-make-bed-blocking-worse/>

councils the risk is also that delayed discharges will rise resulting in even greater costs for hospitals as a result of DLA plans.

Despite requests, DWP have not outlined how the government has worked to ensure one department does not act in a silo and ignore costs to the Department of Health budget as a result of DLA plans.

3) Potential impact of DLA plans on councils

In the Disability Alliance survey, 14% of respondents suggested an increase in need for council support would be the outcome of losing DLA. At that time, the government had not published estimates for how many disabled people would be made ineligible for support. DWP now estimate 500,000 disabled people will lose eligibility. If 14% sought council help the most likely source of help would be social services and this would represent 70,000 people.

The NHS Information Centre recently published its latest report on the costs of personal social service expenditure²⁹ which provides useful evidence for analysing the potential impact of the government plans.

Many families reported, in the Disability Alliance survey, that they would need residential care placements for loved ones if they lost the financial means to support people at home. Disabled people also suggested moving to care homes to avoid being 'burdens' on families. This raises essential Human Rights issues about families losing the ability to live together. But, in solely financial terms for this analysis, 70,000 disabled people needing residential care is not inexpensive and should have been considered by government in developing PIP plans.

The average cost of adult care in 2010/11 was £623 per week; this compares economically unfavourably with the £70 average weekly DLA payment.

One person needing a council funded care home placement would cost £32,396 per year. If all 70,000 needed such financial support as a result of no longer being able to manage at home, the total is up to £2.3 billion per year. It is an incredible oversight by DWP to exclude any analysis of this issue. Whilst not all these people will seek and/or receive residential care placements funded by councils, if just 10% of this figure was realised the additional costs to local authorities would be £226.8 million a year.

If people were supported in their own homes by councils the cost would fall dramatically, with the average being £204 a week (£10,608 a year). Even if all 70,000 were able to be supported in their own home this would still represent

²⁹ See:

http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/pssexpcosts1011/Final_Report_PSSEX1_201011.pdf

a new cost to councils of £742.6 million a year. This would also contradict the responses from disabled people and their families highlighting care home needs if DLA or an alternative financial payment was no longer available.

In the context of councils reducing support through social services and facing significantly reduced budgets from central government, it seems very unlikely disabled people would be able to access alternative support to this scale from local authorities.

24% of DLA (and the older people's equivalent Attendance Allowance) recipients already pay for care services according to DWP³⁰. It seems even more unlikely that families will, with lower incomes, be able to pay more for services. This presents a further dilemma for councils as potentially less income is available to provide support at local level. In the context of diminished central government funding for councils and rising demand for support, a further outcome of DLA abolition for working age disabled people will be even further restrictions on social services.

This potential demand for council support comes on top of the existing social care crisis³¹. The restrictions on care services disproportionately affect disabled people. Restrictions also disproportionately affect women, due to higher employment levels of women in care sector (82% of the adult social care workforce are women³² and the informal care pressure resulting from a lack of social services that falls to women³³.

The UK has a high rate of economic inactivity due to informal care provision³⁴. This issue is also one of growing national importance, especially in the context of struggling economic performance. A social care white paper is due in May 2012 and we hope it will include estimates for the rising cost to meet demands individual disabled people and families can no longer manage due to lost DLA support.

It is no coincidence that the Dilnot Commission into funding care and support recommended retaining universal benefit payments³⁵. The Commission received evidence from disabled people, carers and older people and their representative organisations on the issue of DLA, Attendance Allowance and

³⁰ See: <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep649.pdf>

³¹ See Age UK's campaign on the social care crisis at: <http://www.ageuk.org.uk/get-involved/campaign/poor-quality-care-services-big-q/>

³² See:

http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/Pssstaffsept11/Personal_Social_Services_Staff_of_Social_Services_Departments_11.pdf

³³ 60% of carers are women; see: <http://www.carersuk.org/newsroom/item/57-failure-to-invest-is-widening-inequality>

³⁴ See: <http://www.statistics.gov.uk/hub/labour-market/people-not-in-work/economic-inactivity>

³⁵ See: <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf> and the recommendation on universal benefits is on page 6, point 4: "Universal disability benefits for people of all ages should continue as now".

the ability to manage care needs without formal service support.

Total potential costs

This report is not meant as an exact estimate of total costs, we are purely demonstrating the need to ensure government and others consider the full implications of welfare cuts before viewing DLA as deadweight expenditure and suggesting a 20% cut in expenditure will not result in other government costs.

This is especially relevant given the Chancellor's statement during the 2012 Budget announcement in the House of Commons that a further £10 billion may need to be cut from welfare spending if the economy doesn't improve.

Using the conservative estimate of 25,200 disabled people losing work (as a result of 500,000 less disabled people being eligible for DLA/PIP) and using the average annual income in the UK:

- the Treasury loses £146.7 million annually in NI/income tax;
- out of work benefits cost DWP between £90.8 million (at JSA rates) and £127.7 million (at lower ESA rates) annually;
- additional out of work benefit assessments cost £3.2 million (over three years); and
- PIP assessments cost £675 million (to 2015/16).

Using the higher 50,400 estimate for disabled people potentially leaving work through losing eligibility for DLA:

- the Treasury loses £293.3 million annually in NI/income tax;
- out of work benefits cost DWP between £181.7 million (at JSA rates) and £255.4 million (at lower ESA rates) annually;
- additional out of work benefit assessments cost £6.5 million (over three years); and
- PIP assessments cost £675 million (to 2015/16).

These are purely the work and assessment costs. NHS and council social care costs are also relevant:

- the cost of one GP appointment per person going through the PIP assessment process could be £132 million (over three years);
- if just 16% of the 500,000 losing eligibility required just one further appointment with a GP this is the equivalent of 80,000 additional appointments and a further £4.8 million cost a year to the NHS;
- one average hospital stay for 16% of the people losing support could see an additional £120-£144 million annual cost to the NHS;

- if 14% of the disabled people losing DLA required help from council social care services this is 70,000 people and the annual cost could be between £742.6 million and £2.3 billion a year (a large variance as a result of the wide difference between homecare and residential care costs to councils).

These figures are estimates but reveal some potentially very high costs of abolishing DLA for working age disabled people. The lowest annual costs using the figures above could be £1.4 billion – or two thirds of the total expected reduction in DLA expenditure. It includes 70,000 disabled people going on to access local authority social homecare services; without this social care cost the low end estimate is still £629.2 million a year (almost a third of the targeted reduction in expenditure).

But our lowest estimates requires disabled people losing work to access JSA (an unlikely outcome for many thousands of disabled people), excludes other potential benefit costs (housing benefit in particular), uses low healthcare expectations, and excludes care assessment costs at local level.

If 50,400 disabled people lose work and access ESA (work-related activity group) this could result in costs to government of as much as £965.5 million annually. This excludes additional likely health and social care costs caused by losing access to DLA/PIP.

The worst case scenario outlined above being actualised could result in highest possible costs to government including an additional 70,000 disabled people requiring council-funded residential care placements at £2.3 billion (i.e. above the benefits, Treasury NI/income tax losses, NHS and assessment costs outlined above).

Because these figures are not all DWP costs (reaching into the NHS and councils) we believe they have been overlooked in the pressure to reduce welfare expenditure. But consideration of cutting welfare has appeared to view DLA payments as deadweight expenditure. The idea that DLA represents a 'nil return' means of supporting disabled people is inaccurate and it is essential discussions occur in the context of facts and strong analysis.

An estimated £9 billion is already set to be cut from disabled people's support in this Parliament³⁶. Disabled people feel 'Hardest Hit' by current reductions in support³⁷ but the Chancellor has warned of a potential further £10 billion to be axed from welfare spending if economic recovery is slower than anticipated.

³⁶ Scope/Demos 2010, see: <http://www.demos.co.uk/projects/disabilityausterity>

³⁷ The 'Hardest Hit' campaign information is online at: <http://thehardesthit.wordpress.com/>

With disabled people potentially prevented from contributing to the economy through lost work, this fear may be realised unless DWP ensure reductions in support are closely monitored and reviewed.

Response to specific consultation questions

Our responses to the main consultation questions are below.

Q1 – What are your views on the latest draft Daily Living activities?

The draft activities are an improvement on the first version but would still represent a significant barrier to accessing support to disabled people even with very high support needs.

We welcome the new ‘making financial decisions’ activity and suggested a ‘managing money effectively’ activity in our response to the initial consultation. We are pleased the government is acting on some concerns of disabled people and disability organisations like ours. However, a large numbers of challenges still remain in the proposed criteria and weighting which we focus on below.

Essential activities

The consultation document (‘PIP: second draft of assessment criteria’) states that DWP aims to “create criteria which accurately assess the impact of all impairments”. This ‘capturing’ aim is essential given DLA helps cover some of the associated costs of the wide range of impairments and health conditions which recipients experience, from psychosis to physical and sensory impairments as well as learning disabilities and long-term health conditions like HIV/AIDS. It is also essential that DWP ensures people with multiple impairments are able to access support from the DLA replacement benefit; evidence demonstrates that 91% of the disabled people receiving DLA have more than one impairment and over half (56%) have four or more impairments³⁸. Our confidence that DWP will meet these essential aims using the proposed descriptors and weighting is low.

The proposals aim to use a descriptor activity assessment and points based system. This approach is similar to the operation of the Work Capability Assessment (WCA) method used since 2008 as one means of measuring people’s ability to work. Sadly, disabled people’s confidence in the WCA approach is at an all time low with increasing evidence of the link between the

³⁸ Sainsbury, R et al *Evaluation of Disability Living Allowance and Attendance Allowance*, 1995. Department of Social Security Research Report No. 41. See: <http://research.dwp.gov.uk/asd/asd5/rrep041.pdf>

testing system and suicides of people losing support³⁹. The government must approach a similar system for PIP with great sensitivity and caution.

The WCA is comprised of fifteen non mobility activity descriptors. But the proposed PIP daily living activity descriptors comprise of just nine descriptors.

In comparison to both of these tests, the assessment for DLA – separate from the need for supervision – considers the need for support with daily personal actions ('bodily functions') including: hearing, eating, drinking, seeing, washing, shaving, reading, communicating, walking, sitting, sleeping, getting in and out of bed, dressing or undressing, getting in and out of a chair, using stairs, getting to and from and using the toilet, help with medication and thinking.

The difference is stark; for DLA, anything to do with the body and its functions can count. For PIP the assessment is much more restrictive and will impede many disabled people accessing support.

One of the failures of the WCA has been its inability to identify disabled people's needs effectively. The rigid, tick-box approach of the WCA has prevented many disabled people accessing appropriate support. The proposed PIP assessment also risks repeating this prohibitive approach.

This marks a major departure from the criteria and principles of DLA, introduced in 1992 to help with higher costs relating to any impairment/health condition. As a result, support will be removed for large numbers of disabled people who will experience a reduction in ability to exert control and be unable to achieve independence or avoid poverty as a direct result.

Moving around

DLA helps with a wide range of needs but, under the proposed PIP daily living activities, help with the following will not be considered:

- getting in/out of bed;
- getting in/out of a chair;
- using the stairs;
- moving around indoors;
- getting to and from the toilet; and
- getting in/out of the bath.

³⁹ For national and local examples see: <http://www.guardian.co.uk/politics/2011/feb/23/government-reform-disability-benefits> and <http://www.formbytimes.co.uk/news/formby-news/2012/05/17/dad-s-fight-for-justice-after-son-died-six-weeks-after-his-benefits-were-cut-100252-30986134/#.T7aGHV2jr3x.twitter>

This will, of course, prevent disabled people accessing support to meet very basic needs, including getting around the home.

In terms of providing an objective, consistent and holistic assessment of an individual's ability to participate in every day life, it is essential that disabled people's ability to move around indoors is considered. For many disabled people, particularly those with musculoskeletal conditions, the difficulties in moving around the home present the greatest obstacles and risks in carrying out activities fundamental to everyday life.

For instance, for someone with severe osteoarthritis the greatest challenge to using the toilet may be getting to the room. They may be able to manage inside the bathroom unassisted due to adaptations, but cannot get there safely without support.

Activity 11 (moving around) is specifically limited in the technical notes to the 'physical ability to move around **outdoors**' [our emphasis]. This prevents some disabled people being able to access essential support to undertake the DWP identified essential activities (rendering them inessential despite their very basic nature).

We therefore strongly recommend (again) that a new activity of movement indoors is introduced, with descriptors that focus on the following:

- moving from room to room;
- getting into and out of bed;
- getting in and out of chairs (or transferring from and to wheelchairs);
- negotiating stairs; and
- turning over and changing position in bed.

Supervision needs and staying safe

We are very concerned that the proposed assessment will not ensure disabled people are able to remain safe. DLA provided significant measures to ensure 'supervision' support was accessible: the PIP proposals provide an insufficient focus on this area and represent a worse than 'DLA Lite' approach.

On this issue (and following feedback DWP received on initial plans), the consultation document states that:

'A lot of the feedback we received questioned why the initial proposals did not reflect the need for supervision to ensure an individual's safety while carrying out activities. We have recognised and addressed this in

the second draft of the criteria. The descriptors now take account of whether an individual requires 'supervision' from another person – defined as their continuous presence throughout the task to prevent a potentially dangerous incident occurring. This approach is very similar to that currently taken in Disability Living Allowance.

'The broader definitions used in the second draft enable the assessment to reflect support required from another person more accurately. Requiring support for only part of the activity and taking account of the need for supervision should ensure that the assessment better captures the impact of impairments.'

However, the revised descriptors/weightings do not seem to meet this statement's sentiment. The only PIP daily living activity descriptors that now specifically consider the potential need for supervision are:

- preparing food and drink;
- managing therapy or monitoring a health condition; and
- bathing and grooming.

We are very concerned that the draft activity tests do not take into account the full range of needs that currently fall within the 'continual supervision' criteria of the care component of DLA. This represents a significant watering-down of support and does not redress the imbalance identified by disabled people and disability organisations to date.

For example, someone with severe epilepsy may qualify for the current DLA care component on the basis that they require someone with them ready to take action to avoid injury if they have a seizure. The only descriptor that would appear relevant to such a situation would appear to be 1(E) – needs supervision to cook a simple meal.

The inadequacy of the PIP consideration of supervision is rather aptly (but unintentionally) highlighted in case study 4 of the assessment thresholds consultation paper:

'Pete is 19 and lives with his family. He does administrative work for his father's roofing business, working from home as he is not allowed to drive because of regular epileptic fits. He loves to watch sports, particularly football, but is unable to take part as he is worried about having a fit. These have been more frequent since puberty and his neurologist keeps his treatment under constant review to try to reduce his fit frequency; he is currently having a mix of either grand-mal or petit-mal fits most days and sometimes more than once a day.'

'He is occasionally incontinent during a grand-mal fit and falls asleep for a while afterwards. Between fits he is fairly independent though he only takes a shower if a family member is in the house and he never cooks when alone – in the past he has suffered injuries including scalds and burns in the kitchen. He has little or no warning of a fit and previously he has received cuts and bruising from fits while outdoors. He never goes out unaccompanied because of the risk and danger from traffic.

Total points

Daily living activities = 6 (no Daily Living component entitlement)

Mobility activities = 15 (enhanced rate Mobility component)

Explanation

Although Pete has fits on most days, which are unpredictable with minimal warning, he is independent in all daily living activities other than cooking and bathing, where having a seizure would result in significant risk. He therefore requires supervision for these activities. He requires supervision whenever he goes out, because of the significant risk of injury.'

However, it is very probable that Pete would be awarded the middle care rate of DLA on the grounds that he reasonably needs continual supervision to avoid substantial danger to himself.

Yet while he would qualify for the PIP mobility component as he is at significant risk of injury when he goes out, he would not qualify at all for the daily living component.

In addition, there is no recognition in the draft activity test of the risks faced by people who are prone to falls generally. Activity 11, moving around, refers only to the ability to get around outdoors. There is little recognition at all that many disabled people have difficulty moving around indoors, and may require someone to be with them because of the risk of falling. Someone may well be able to manage on their own whilst actually using the toilet, but still require someone with them whilst climbing the stairs to reach the toilet because of unsteadiness or poor balance. If DWP are under an illusion that all disabled people live in accessible homes, or that Disabled Facilities Grants reach all disabled people requiring them, Disability Rights UK is happy to help provide a clearer picture.

We would highlight that for the purposes of PIP, supervision should be 'reasonably required' rather than medically required. For example, a disabled person may be mentally alert and know what they cannot do without someone's support on hand. Medically speaking, people can supervise themselves. But, in practice, people supervising themselves might mean that to avoid the risk of danger the only option is to stay in bed or live in an

armchair. We do not believe the government's intention is to create such circumstances being the only option for disabled people – who are being urged to participate and contribute to a greater degree than ever before through changes to other benefits and reductions in other support. DWP believe this will 'incentivise work' but the PIP proposals risk preventing participation occurring if such genuine support and supervision needs are not identified in the assessment process.

The underlying question is one of whether or not people reasonably require supervisory support from someone else in order not to overly restrict participation and involvement in activities. PIP must be designed to support participation and ensure disabled people are enabled to continue what might be termed 'a normal life'. The current plans may restrict life to an 'armchair existence' to avoid risks of attempting to manage tasks personally. Under the current system, if restrictions on lifestyle are unreasonable DLA recognises that people reasonably require supervisory support from another person. PIP would abolish this personalised approach and prevent support being delivered.

People with certain mental health conditions or cognitive impairments may place themselves, or others, in danger either through deliberate action or an inability to take normal precautions. The only recognition in the PIP proposals of this issue appears to be in the context of the possible risks in using a conventional cooker. There is no recognition of any risks arising from the use of, for example, heaters or other household appliances and equipment. In some cases the risks will be similar to those posed by cooking, but in other cases there may be different and even greater dangers.

Some disabled people with mental health problems may be at risk of deliberate self-harm. There is nothing in the descriptors that refers to such risks. 'Managing medication' is defined in terms of taking prescribed medication at the appropriate time. This would clearly include preventing an overdose of valium prescribed by a GP, but it would not appear to include preventing someone from swallowing a bottle of paracetamol bought over the counter.

We are very concerned that there are a large number of disabled people whose need for continuous supervision is recognised under DLA whose support to prevent self-harm needs will not be recognised by the PIP daily living descriptors and so will be denied the new benefit.

We would recommend that either the 'continual supervision' route to benefit is retained in the PIP assessment or that an additional activity of 'staying safe' is added and appropriate descriptors devised. But we regard the retention of the current supervision test as preferable, as it would be more flexible and

responsive in dealing with the wide range of ways in which disabled people may be exposed to danger as a result of their health conditions.

On this issue, the ESA system offers a precedent for this approach. While it attempts to encompass a holistic assessment of someone's physical and mental, cognitive and intellectual functionality, if someone does not accrue enough points to have a limited capability for work they are nevertheless considered to have a limited capability for work if there is a serious risk to their physical or mental health if found fit for work.

We believe it is appropriate that a separate 'continual supervision' route to PIP eligibility is both logical and appropriate.

Assistance at night

At present the middle rate of the care component of DLA is paid to people who need help during the day *or* during the night, and the high rate is paid to people who need help during the day *and* the night.

However, the only potential night time daily activity proposed for PIP is 'Managing toilet needs or incontinence'. But this descriptor is incredibly limited in scope.

Jim is a disabled man, aged 61. He experiences night time incontinence. Due to severe osteoarthritis, he also needs help to get in and out of bed. He also requires support to get to and from his bathroom. But he manages using the toilet once in the room. Under the PIP proposals Jim would not score any points.

We do not believe this is the government's intention. But Jim, and others like him, would experience this practical reality using the current proposals.

Similarly, someone who is incontinent at night may require assistance changing soiled bedding, whereas during the day they might be capable of dealing with soiled clothes themselves (the size, weight and dexterity issues being very different).

Similarly, someone with epilepsy may receive sufficient warning of an attack to take precautionary action during the day, but be unable to do so whilst sleeping. Being able to fund support (someone 'watching over') to ensure no injury should they experience a seizure during the night is possible under DLA but not PIP.

Visual impairment and communication

We are also very concerned that many visually impaired people are likely to have difficulty in qualifying for the daily living component. In terms of DLA, all help with the bodily function of seeing throughout the day counts in terms of quantifying the need and frequency of attention. As a result, people with a visual impairment are often awarded the middle care component of DLA. Under PIP, the restrictive nature of the nine daily living activities precludes full consideration of help with seeing/the built environment.

In addition, the communicating activity separately considers difficulties with written or verbal communication. This does not take into account those disabled people who have difficulty with both written *and* verbal communication.

In short, we are very disappointed with the considerably limited set of essential activities despite the DWP emphasis that the PIP is being designed to support disabled people to be active and independent.

We therefore believe specific daily living activities are required surrounding moving around inside the home, staying safe, and assistance at night and improved consideration of the needs of those with sight and communication problems.

Any failure to provide such support will result in a benefit which fails to meet its core purpose, waters down significant and essential support for disabled people and will significantly disadvantage an already disadvantaged group in our society.

Activities and practical barriers to accessing support

We provide a brief analysis of some of the barriers to accessing support the proposed activities might generate, preventing disabled people with high support needs accessing PIP.

We recognise the government's intention to remove 500,000 disabled people from eligibility but urge careful consideration of how the barriers proposed to accessing support will affect the lives of the disabled people directly affected, their families and carers and the broader public services (including the NHS and council run social services) and their budgets which will also experience a rise in demand as a result of a 'DLA Lite' approach to PIP.

We believe many essential activities are undermined by the points allocated to them and most should receive maximum points to recognise their importance to achieving a very basic quality and standard of life. Failure to provide a more 'recognising' system will mean the PIP plans reduce support

to more than the 500,000 target set by DWP to meet the Treasury savings target. Some examples to highlight this point include:

- Activity 1: preparing food and drink

Under the current plans it appears someone needing to use an aid or appliance *and* needs supervision would receive just 6 points and not qualify for even the standard rate PIP for an essential activity of daily living.

The maximum points for someone unable to prepare and cook food and drink at all seems to be eight. This would result in a standard rate payment and, potentially, a payment of £50 per week. This does not match needs with support and could leave many disabled people without sufficient support or funding.

- Activity 3: managing health

Only one point is available for people needing *constant* supervision to take medication. Many people with mental health problems, including schizophrenia, may require (especially at certain times) support to manage medication which can have a very significant impact if not provided. There seems an imbalance between the support to take medication being available and the eight points available to help manage 14 hours of therapy per week (F in the associated explanatory notes document).

Given the importance of taking medication on disabled people's immediate wellbeing, broader life chances and potentially to later NHS costs (if health is mismanaged through a lack of support) we believe this activity also warrants a greater points allocation (with 12 points could be available for support for medication).

- Activity 4: bathing and grooming

We responded on this issue in the first consultation, including at a meeting with our members organised jointly by us and DWP. We were assured that DWP had listened to concerns about the different support needs arising from toileting and menstruation. We were also assured that the next stages of developing the PIP assessment plans would address the essential need to keep the whole body clean. We feel very poorly let down that these issues are not adequately addressed – and even undermined – by current plans.

We do not accept that the government wants disabled people to be unable to keep the whole body clean. But the current plans do not include the full body and seem, largely, to stop at the waist.

On toileting, for example, DWP seem focused solely on washing the perineum, rather than ensuring general cleanliness after defecating.

On bathing, disabled people appear to have no need to ensure legs and genitals are kept clean under existing plans – or that toenail care is required.

‘Needs assistance to bathe’ is worth just four points. It seems a more appropriate minimum would be far higher and at least eight. We acknowledge that DWP suggested in our meeting with members on 30th April that disabled people would ‘accrue points elsewhere’ and ensure PIP is accessed via this route. But this ignores the essentiality of each descriptor/activity and the impact of failing to have needs identified (as occurs under the similar WCA which includes a far greater level of activities).

We are very surprised that the maximum points allocation for this activity for disabled people who ‘cannot bathe and groom at all’ is eight and would only secure the standard rate of PIP payment for daily living support. Being unable to bathe is clearly demonstrative of high support needs and an enhanced payment for this activity would seem appropriate.

- Activity 5: managing toilet needs or incontinence

We believe the proposals fail to include the management of the consequences of incontinence. Cleaning bedclothes or attire is relevant – as is the ability to undertake the strenuous activity involved.

A disabled person needing assistance to manage incontinence of the bowel would only receive six points in the proposed weighting system. This would not result in receipt of PIP. We cannot believe it is the government’s intention to deny support to disabled people unable to control continence of the bowel, but this is the reality for people who only receive points under this criterion.

We are concerned that the plans do not include getting to the bathroom/toilet, or changing clothes.

- Activity 6: dressing and undressing

A disabled person needing assistance to dress the lower anatomy may only get three points under the current plans. Practical examples focused on this issue have been raised by the Thalidomide Society and we hope the next stages of the assessment’s development will fully address concerns.

Failure to address the concern could mean someone unable to dress themselves below the waist and requiring support for managing toilet needs (valued at just four points despite its critical nature to daily life and ability to participate) would still not be able to access PIP. Disability Rights UK does not believe the government’s plan was to axe support for people who could experience these circumstances, but this is the practical potential under current plans.

- Activity 7: communicating

We do not believe the low points available for requiring a voice synthesiser reflect the potentially high communications and support needs of disabled people.

Disabled people needing assistance to understand written communication would also only receive four points. There were (at November 2011 and using DWP statistics⁴⁰) 230,000 disabled people of working age (16-64) with learning disabilities recorded as their 'main disabling condition'. DWP must take care to ensure this group does not experience discrimination in the new assessment process of the kind likely if the ability to understand DWP communications is undermined from the outset and points are not available to reflect the lifelong communications needs of this disadvantaged group of disabled people.

- Activity 9: making financial decisions

Financial decisions are essential to every day life. For people receiving benefits the government is moving to monthly payments to one household member. But for disabled people who 'cannot make financial decisions at all' there are just six points allocated under current plans.

Given a third of disabled people already live in poverty and experience high debt, and in the context of the government agenda, it would seem more appropriate to ensure disabled people are able to access support to ensure adequate financial competence is possible.

However, we believe it would be more appropriate for the descriptor to refer to assistance rather than only prompting. This is because it otherwise focuses on cognitive ability rather than take a holistic approach and also include potential physical challenges.

For example, visually impaired people experience barriers to independence because difficulties in seeing can prevent people making basic financial decisions and transactions. It can be harder to calculate budgets and manage if all the available information is written down inaccessible. It is also harder to manage and pay bills or plan future purchases where all the relevant information is in inaccessible formats.

- Activity 11: moving around

See our comments above regarding the need to ensure disabled people are able to access support to get about indoors as well as outside the home.

⁴⁰ See:

http://83.244.183.180/100pc/dla/disabled_new/cnage/ccclient/a_carate_r_disabled_new_c_cnage_p_ccclient_working_age_nov11.html

Q2 – What are your views on the weightings and entitlement thresholds for the Daily Living activities?

We have previously raised concerns about the failure under PIP to provide a 'low rate care' equivalent. While DLA has three levels of care components PIP is proposed to have only two daily living activity components – standard and enhanced. Low level care under DLA reached 586,000 working age disabled people in 2011⁴¹ and we believe its abolition will:

- undermine support for disabled people (especially people with mental health problems and fluctuating conditions) unable to access help elsewhere (due, for example, to local authority eligibility for care services being raised significantly since DLA was introduced);
- have long-term cost implications for the NHS and councils (due to people losing the ability to manage low level health and care needs);
- prevents the 'early-intervention' or 'preventative' care agenda being delivered; and
- ignores the Dilnot recommendation which suggested universal benefit entitlement remain at DLA levels.

The abolition of this rung of support inevitably means that the proposed weightings are likely to exclude most of the 586,000 disabled people who currently receive the lower care component of DLA. But the government has not fully analysed what the impact will be – or how this level of care was accessed.

For example, someone is eligible for the lower care component of DLA solely if they cannot prepare a cooked main meal for themselves without the help of another person. In contrast, someone who can prepare a cooked main meal with the help or supervision of another person will only score four points under PIP and therefore will not be eligible for even its standard daily living activity component.

There are many reasons why someone may not be able to prepare a cooked main meal unaided – for example pain, manual dexterity, chronic fatigue, depression or a learning disability. Many disabled people receive support from a relative, neighbour or friend to cook regular meals for them and will use their lower care component of DLA to reward them for this service and to ensure that it is maintained.

⁴¹ See:

http://83.244.183.180/100pc/dla/carepay/cnage/ccclient/a_carate_r_carepay_c_cnage_p_ccclient_working_age_nov11.htm

It is difficult to see how removing benefit from particularly those disabled people who live alone can do anything but harm their long term physical health – with negative consequence at the individual level but long-term financial implications for government expenditure.

The proposed weightings also place a greater (often double) emphasis on the need for physical help with the specified daily living activities than prompting and encouragement to undertake and complete them.

For example, prompting to cook a simple meal attracts two points whereas needing assistance to cook attracts four points, with prompting to bathe scoring two points whereas needing help to bathe attracts four points. This can only result in making it much more difficult for someone who receives support throughout the day due to severe mental health problems – such as depression or dementia – to qualify for PIP.

For the purposes of DLA there is no distinction between the importance of physical care and that done by prompting and encouragement and we believe this should be the case with PIP.

The ‘Managing therapy or monitoring a health condition’ activity is strikingly low scoring with only one point being scored for needing supervision, prompting or assistance to manage medication or a health condition. With this descriptor’s stated aim is to consider a disabled person’s ability to manage their condition to ensure that their health does not deteriorate any points awarded must better reflect this.

This descriptor is also intended to take into account ‘supervision due to the risk of accidental or deliberate overdose or deliberate self harm is captured in these descriptors as the person would require support from another person in order to prevent this’. In an individual case such supervision might take up all of the day and such monitoring therefore needs to be scored accordingly.

We would highlight our earlier points with regard to the deficiencies within the proposed daily living activities with respect to the consideration of a disabled person’s need for supervision.

While we believe it would be an inadequate solution in isolation, in the scoring and the thresholds when someone is unable to do something without supervision it should score the same as assistance and qualify someone for at least the standard rate.

Q3 – What are your views on the latest draft Mobility activities? And Q4 – What are your views on the weightings and entitlement thresholds for the Mobility activities?

The consultation document suggests:

‘For the Mobility component, the proposed thresholds reflect and differentiate between the extra costs incurred by an individual requiring support to get around.’

Under DLA, the lower mobility component is available to those who can walk but cannot take advantage of this outdoors unless accompanied by someone who can guide or supervise them due to physical or mental disability. And the higher mobility component is payable to those who have a severe physical walking impairment or are severely mentally impaired with extreme disruptive and behavioural problems and high day and night care needs.

Whilst PIP is proposed to have a standard and enhanced rate in a similar style to DLA, we believe that the make-up and weightings of the mobility activities will mean that many disabled people will not qualify for either, particularly those who now qualify for DLA lower mobility component. The consultation document makes clear that 280,000 disabled people who would have been eligible for high rate mobility under DLA by 2015/16 will no longer be eligible for PIP. This is likely to result in Motability removing 90,000 accessible vehicles and scooters for example from the road. It is hard to envisage this having anything other than a detrimental effect on disabled people's equality of opportunity and ability to participate/live independently.

The category B ‘Planning and following a journey’ activity requires that someone ‘need prompting for all journeys to avoid overwhelming psychological distress’. It is unclear whether this would include people who experience anxiety or panic attacks, the fear of which can often prevent people going outdoors. Category B also only attracts four points and so would not result in a PIP mobility award.

It is difficult to see why DWP would conclude that is appropriate to make disabled people who need to be accompanied outdoors to avoid ‘overwhelming psychological distress’ ineligible for PIP.

Category D of ‘Planning and following a journey’ refers to the inability to follow any journey because it would cause ‘overwhelming psychological distress’ scores ten points and also fails to result in a PIP mobility award. It is less than clear if it would be applicable to those who have great difficulty coping with unexpected changes in a planned journey, for example due to cancelled trains or rerouted buses and including substantial numbers of people with learning disabilities.

In terms of the 'Moving Around' activity (11), it is stated that this will consider an individual's physical ability to move around.

We believe DWP must clarify how issues such as 'severe discomfort' will be taken into consideration as is the case with the DLA higher mobility component that considers factors such as pain, breathlessness, and fatigue. We believe DWP wishes to avoid complex case law developing and suggest upfront definitions to be open to formal consultation at the earliest juncture.

While considering distance, the DLA higher mobility component also considers the speed, time and manner of a disabled person's walking. In contrast, the 'Moving Around' activity solely considers mobility over 50 metres. This massively restricts independence and risks withdrawing support from considerable numbers of disabled people.

There is also a significant point's demarcation between Moving around. Category D states: 'Cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device (10 points)' and category E states: 'Cannot move up to 50 metres without using a wheelchair propelled by the individual (12 points)'. People meeting the terms of either category D or category E would undoubtedly both be awarded the higher rate of the DLA mobility component. However, in terms of PIP weighting, category D attracts only a standard Moving around award with category E attracting an enhanced Moving Around award.

There is a significant difference in the weekly amounts of the DLA lower mobility component and higher mobility component – currently £20.55 and £54.05 (a difference of £33.50 a week). This is to reflect that those who have severe physical problems getting around outdoors inevitably will have higher transport costs and may often need to make use of private transport (whether or not they are a wheelchair user).

We would therefore submit that both those who meet category D and Category E should be awarded the enhanced PIP mobility component.

In addition, this is an appropriate match to the DWP indication that only those awarded the enhanced Moving Around component will be eligible to take advantage of the Motability scheme.

Q5 – What are your views on how the regulations work regarding benefit entitlement?

To avoid repetition, please see answer to Q9.

Q6 – What are your views on how we are dealing with fluctuating conditions?

The intention to use a 'more than 50% of days' definition ignores the severity with which someone can be affected by a health condition or impairment – and the costs involved – for just one month for example. As an example, Debra represents people who experience Epidermolysis Bullosa. Some people affected by this kind of unusual condition may only be affected at specific times of the year (and other skin conditions are also aggravated by outdoor temperatures and sweat for example). Other disabled people will experience higher but intense needs for short periods in winter. DLA has been used to help disabled people towards higher utility bills for air conditioning units in summer and heating in winter. It is likely that the more than 50% rule will deny help to some disabled people with very high needs.

We do acknowledge the 'logic' of requiring a disabled person to meet a descriptor on 'more than 50% of days'. However, we are very concerned that it is likely to be difficult for many disabled people to calculate or independently verify that this has been the case.

This is perhaps particularly so when people make a first claim for PIP as they will be unlikely to have kept such a detailed diarised monitoring of circumstances/difficulties dating possibly back 12 months that would definitively indicate their situation on 50% of previous days.

We also perceive a clash in this requirement when taken in conjunction with the proposed requirement to satisfy the daily living and/or mobility activities test for 3 months prior to claiming and be likely to continue to satisfy this test for a period of at least 9 months after claiming.

For example, it is possible that a disabled person with a fluctuating condition may have met the daily living and/or mobility activities on more than 50% of days in the 12 months prior to their PIP claim but not on 50% of days in the 3 months preceding it.

Q7 – What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

It is now a legal requirement the assessment of someone's limited capability for work under the WCA must take into account their the ability to perform descriptor tasks 'safely', 'timely', 'repeatedly' and 'in a timely' manner. This follows the determination of ESA appeals by Social Security Commissioners and Upper Tribunal Judges that this should be the case.

Reliably means to a reasonable standard.

In a timely fashion means in less than twice the time it would take for an individual without any impairment.

Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

Safely means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

We welcome the DWP stress that the PIP assessment will require assessment of an individual's ability to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. If this is not possible, the disabled person should be considered unable to complete the activity described at that level.

We believe that it is essential that both the definitions of reliably, repeatedly, safely and in a timely manner are both:

- incorporated in regulation 1 the PIP assessment Regulations (Interpretation); and
- incorporated as a requirement of regulation 4 (Determination of limited and severely limited ability to carry out activities).

To do so will make it clear to those required to carry out PIP face to face assessments of the requirement to take into account the need to consider an individual's ability to carry out an activity reliably, repeatedly, safely and in a timely manner. This approach could also mean it is more likely that assessments are carried out in a consistent manner.

Q8 – What are your views on the definitions in the regulations?

The Disability Benefits Consortium (DBC) has commented that the regulations definition of aid and appliances is inadequate:

“aid or appliance”-

- (a) means a device to improve, provide or replace a physical or mental function;
- (b) includes a prosthesis; and
- (c) does not include an aid or appliance ordinarily used by a person without a physical or mental condition which limits that person's ability to carry out daily living or mobility activities;

This is on the basis that a disabled person may rely heavily on a mainstream device. We support the DBC concerns.

Q9 – Do you have any other comments on the draft regulations?

The proposals will reflect the descriptors, assessment process and overarching plan to remove eligibility for 500,000 disabled people who would otherwise have been supported by DLA. We have significant concerns about the proposals and their potential impact.

We will, of course, be seeking further improvements in the process, descriptors and activities and regulations as they are developed.

Contact/further information

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